

Batten Fighters Forever
Trustee Report and Financial Statements
Year Ended 31st March 2021

Charity Number: 1182753



Reference and administrative information

Trustees

Andrew Hover, Chair of Trustees

Lisa Hover, Treasurer

Sarah Sillince

Sarah Horton

Chris Horton

David Worn

Registered Office

4 Ashley Cottages, Verwood Road, Ringwood, BH24 2D

Charity Number

1182753

Bank

Barclays Bank, 6-8 High Street, Ringwood, BH24 2BZ

Report of the trustees for the year ending 31st March 2021

The trustees present their annual report and financial statements of the charity for the year ended 31st March 2021. The financial statements have been prepared in accordance with the charity's constitution and the Charities Act 2011.

Structure, governance and management

Batten Fighters Forever is a registered charity, number 1182753, and was constituted as a charitable incorporated organisation on 2nd April 2019. The charity was established by the current trustees and no trustees have been added or removed.

At the quarterly trustees' meetings, the trustees agree the broad strategy and areas of activity for the charity, including consideration of grant making, fundraising, awareness raising, reserves and risk management policies as well as monitoring the performance of the charity. The day to day management of charity activities, including but not limited to the administration of grants and handling of grant applications prior to review by the trustees, is delegated to the Chair of Trustees and the Treasurer.

All trustees give of their time freely and no trustee remuneration was paid in the year. There were no trustee expenses paid in the year. Trustees are required to disclose all relevant interests, register them and in accordance with the charity's policy withdraw from decisions where a conflict of interest arises.

Risk Management

The trustees have considered the major risks to which the charity is exposed, have reviewed those risks and established systems and procedures to manage those risks.

The trustees have established a data protection policy and implemented practices to reduce exposing sensitive information of anyone supporting or being supported by the charity in line with requirements of the General Data Protection Regulations.

Our main operational risk for the forthcoming period will be the remaining impacts of the COVID 19 pandemic on fundraising and awareness raising opportunities. The Trustees reduced the income forecast in the charity's business plan for the 2020-21 year to recognise the number of planned fundraising events that had to be cancelled. Thankfully this reduced forecast was exceeded but income was 55% lower than the prior year. As the UK recovers from the pandemic, we are hopeful that we are able to organise more fundraising events this year however do not anticipate a completely normal year – the Trustees have again factored this into the income forecast for the 2021-22 year. Grant applications will only be approved by the trustees where funds allow and without impacting the reserves policy.

Objectives and activities for the public benefit

The objects of the charity are to assist in the treatment and care of people with Batten Disease by:

1. Providing information about Batten Disease and where practical help and support can be found.
2. Raising public awareness about Batten Disease and how research into the disease and support for people with the disease, their families and carers will improve the conditions of life for people with Batten Disease.
3. Making grants to
 - a. Pay for personal care, equipment and home adaptations for people with Batten Disease
 - b. Assist in the provision of practical help, advice, support and respite care for people with Batten Disease, their families and carers
 - c. Fund research into Batten Disease and the treatment of the disease, provided the useful results of such research are published.

The charity carries out these objectives by:

1. Providing and continually developing the Batten Fighters Forever website and printed materials as resources to explain about Batten Disease and provide links to practical advice and agencies able to assist people with Batten Disease, their families and carers. Additionally, the website contains blogs, details of the charity, fundraising events and activities.
2. Utilising Facebook, Instagram and Twitter as an integrated social media programme to publish news, updates, information, campaigns, appeals and lobbying.
3. Grant making to assist families and others supporting children with Batten Disease or to support research into treatments for Batten Disease. The grant making is the primary focus of all fundraising activities.

By focussing on these areas, and with regard to the Charities Commission's public benefit guidance, the trustees' achieve the strategic priorities of the charity.

Grant making policy

The charity has established a grant making policy to achieve its object for the public benefit to provide funds:

- To provide support to children with Batten Disease and their families
- To provide support to other charities and organisations that support children with Batten Disease and their families
- To fund research into the disease and the development of medicines for the treatment of Batten Disease

The grant making policy is reviewed annually to ensure that it reflects the charity's objects and thereby advances public benefit.

The beneficiaries of our grant making programme this year have been supported in a variety of ways including mobility aids, iPads, seizure monitoring and home adaptations.

We continue to coordinate with the Batten Disease Family Association (BDFA) both in regard to a number of family grant applications via their family support officers and also to ensure clear delineation between our grant making programme and any small grant provision by the BDFA. We have supported the BDFA with funds to update and produce information folders issued to families with Batten Disease.

The number of enquiries regarding the grant programme increased significantly and the number of submitted applications increased by 50% compared to the prior year. The total value of grants awarded this year was similar to the prior year. The drop in income did not prevent the Trustees supporting all grant applications that were submitted. We will continue to publicise the grant making programme as broadly as possible and encouraging applications from families who require support.

Achievements and Performance

For the year ending March 31st 2021 the following provides a summary of achievements and performance of the charity:

1. Funds raised totalling £7,355 exceeded the charity's fundraising target for the year of operating by 47%. The income target was reduced significantly by the Trustees to account for the impact of the COVID 19 pandemic. Voluntary donations continue to be the largest source of funds.
2. A number of families have received direct support via the charity's grant programme. This has supported children this year suffering from CLN1, CLN2, CLN3 and CLN6 variants of Batten Disease across a broad age range. The grants have supported equipment purchases, mobility aids and home adaptations.
3. Progress has been made with raising awareness of Batten Disease and the support needs of people with the disease and their families.
 - a. The already fairly large following of BFF on social media has grown over the year. Facebook continues to be the medium that provides the most opportunities for interaction and has seen the most activity. Key metrics that we monitor demonstrate this:
 - i. number of people following the page has grown by 9% (increase prior year was 7%)
 - ii. number of people liking the page has grown by 8% (6% prior year)

Financial review

The charity's work is entirely reliant on income from fundraising events and voluntary donations. We exceeded our year 2 income target and had a total income of £7,355. We paid grants totalling £7,197. After expenses, we have a surplus greater than that planned by the trustees.

Reserves policy

The trustees aim to maintain an unrestricted reserve of £1,000 for the purpose of cash flow to manage expenditures for the running of the charity. Reserves at the end of this year are much higher as a result of the surplus carried forward from the prior year, higher than target income and lower than target grant provision. The trustees, however, believe that the target reserve of £1000 is appropriate and will aim to maintain this into next year.

Plans for the future

Our income target for year 2 (2020-21) was adjusted to £5,000 in our business plan to reflect the anticipated impact of the COVID 19 pandemic on our fundraising activities. The income target for year 3 has been adjusted to £8,500 to recognise the easing of restrictions due to the pandemic and to provide a target for diversification of our income channels. We will be focussing on attracting more regular voluntary donors and donations from the commercial sector, not for profit organisations, trusts and foundations.

In the next 12 months we plan to attract grant applications to consume the available funds while maintaining our target reserve.

Trustees' responsibilities in relation to the financial statements

The trustees are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law. Section 133 of the Charities Act 2011 allows charitable incorporated organisations in England and Wales with income of less than £250,000 per year to prepare receipts and payments accounts for each financial year.

The trustees are responsible for keeping accounting records which disclose with reasonable accuracy the financial position of the charity and enable them to ascertain that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities. The trustees are responsible for the maintenance and integrity of the charity and financial information included on the charity's website.

Approved by the trustees on 8th June 2021 and signed on their behalf by:



A. Hover

Chair of Trustees

Batten Fighters Forever
Statement of Financial Activities
For the year ending 31st March 2020

Receipts and Payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds 2021	Total funds 2020
	To the nearest £	To the nearest £	To the nearest £	To the nearest £	To the nearest £
Receipts					
Voluntary donations	6,558	-	-	6,558	12,988
Fundraising events	797	-	-	797	3,275
Total Receipts	7,355	-	-	7,355	16,263
Payments					
Grants Paid	7,197	-	-	7,197	4,045
Costs of generating voluntary donations	71	-	-	71	1,242
Fundraising costs	413	-	-	413	686
Governance costs	-	-	-	-	590
Insurance	160	-	-	160	160
Printing, postage, stationary and computer supplies	96	-	-	96	84
Total Payments	7,937	-	-	7,937	6,807
Net of Receipts/ (Payments)	(582)	-	-	(582)	9,456
Transfers between funds	-	-	-	-	-
Cash funds last year end	10,669	-	-	10,669	1,213
Cash funds this year end	10,087	-	-	10,087	10,669

Assets and liabilities at the end of the period

Categories	Details	Unrestricted funds	Restricted funds	Endowment funds
		To the nearest £	To the nearest £	To the nearest £
Cash Funds	Barclays bank account	10,087	-	-
	Total cash funds	10,087	-	-

Approved by the trustees on 8th June 2021 and signed on their behalf by:



A. Hover

Chair of Trustees